

A canon of the ABLE program is not only the collaboration of practitioner and patient, but the use of “narrative medicine” to allow the patient a way to communicate their frame of reference. By giving patients the tools to relate their own stories, practitioners open pathways of discovery to unknown resilience and life forces in the patient’s life. Expressing one’s narrative can not only be articulated verbally, but through many mediums. The ABLE program focuses on positive aspects of the patient’s life, rather than the traditional pathologizing model, to allow for healing and growth to occur based on the foundation of existing assenting qualities. Michael’s story is one that exemplifies this experience, one of reclamation and empowerment.

A Story on Reclaiming the Life of a Child

Introduction:

The following clinical case is a story, exemplifying the collaborative use of ideas and best practices around social/cultural contexts for securing resilient outcomes with strength-based lifelines. We of the Able Program are privileged to share Michael’s story, as he has taught us in a dozen years a great deal about helping meet the special needs of children with chronic conditions. The main feature of our experience with him was countering the traditional *pathologizing* model of most current interventions which focus on the deficit problem-solving model. The focus was on finding and benefiting from the positive subplots in his life that suggested there were unknown life forces and resilience in operation that could be recruited in the service of individual and family wholeness and completeness. Michael gives us a vision of the multi-dimensional parts comprising a human life that make for a complex whole. We also want to share the artful expressions, pathways and means of our practices, as well as our values and beliefs as they relate to treatment outcomes.



Michael’s Story Personifies the ABLE Program Story:

Michael’s traumatic past included many separations, losses, and unresolved grieving. This was in spite of his having a loving, single parent grandmother who tried to provide for him. Michael was born prematurely and in a crisis. After experiencing a stressed pre-natal environment, his future vulnerabilities included the isolation and lack of social support associated with his natural mother giving him to his grandmother. Ultimately his private pediatrician referred him to our agency and the State early intervention program, as well as a child guidance mental health service. He continued to follow-up on the child’s progress. By using available community services and agencies, she attempted to give Michael what ordinary families provide for themselves through their personal social networks.

Michael was seen during this early phase of his life as high strung, temperamental, and angry. His pre-school and early elementary school experiences were problematic. He showed poor school attendance and classroom failure, was defiant, and was prone to accidents such as falling out a window as a significant traumatic event. He experienced bullying and peer abuse, and through many moves, also dealt with multiple detachments from people and places. He manifested recurrent depression and seizures due to a traumatic brain injury (TBI) from his fall from the window, and was taken many

times to the emergency room early in life. His grandmother's stress and over-reaction increased during this time because she feared for his life and his physical health.

Michael was now showing an inability to master novel as well as ordinary experiences. At this time he was experiencing few planned activities, meaningful events, or healthy social stimulations. Voicing or storytelling his own experiences, discovering new personal resources, or finding his individual knowledge and solutions, were hard to come by within his complex circumstances.

In her efforts to protect her grandson, the grandmother felt alone and became sensitized by early critical events that further altered the anticipated normal course of Michael's development. Her over-protection eventually became overbearing for Michael, as their lives had become highly enmeshed with co-dependency and later ambivalence, as Michael tried to disentangle himself from what had become a counter-productive situation. In time, his real seizures became difficult to differentiate from other spells such as panic attacks. Early adolescent depression continued to plague him and the relationship with his grandmother worsened by dislocations, homelessness, and hostile fighting. Such conditions resulted in the onset of domestic violence and ultimately police and protective services involvement. Grandmother's stories and her own history of victimization by others had also contributed to Michael's increasing paranoia.

From a clinical perspective when such traumatic and depressive experiences are unrelenting and without abatement, they stifle living systems and the mobilization of life forces. Although Michael's intelligence and achievement potential remained intact, his ways of organizing information and communicating his wants and needs were camouflaged and dampened to the point of being inaudible and invisible to others. Consequently, his ability to learn to regulate his own bodily systems and attend to the realities around him, endangered his potential for developing secure attachments, processing reality, developing an adequate perception of the world, in accurately processing information, and developing normal thinking, and remembering.



Although his grandmother was able to mobilize some community resources, including medical insurance, health department services, a physician, social security benefits, and other basic assistance, she was less able to give her grandson a sense of safety, because she had never felt safe herself. In essence, there came a time when Michael's grandmother, his primary caretaker, became herself bereft, depleted, and fatigued from providing Michael with just the physical survival needs. Considering her own unresolved traumas, she couldn't offer what she didn't have, including a secure foundation to model for satisfying Michael's needs for comfort and approval. After all, identity formation is derived from trust, self-control and confidence. These deficits markedly deprived Michael of his own sense of personhood. To help him define a sense of himself and build greater self-capacities, was going to require significantly more personally empowering experiences.

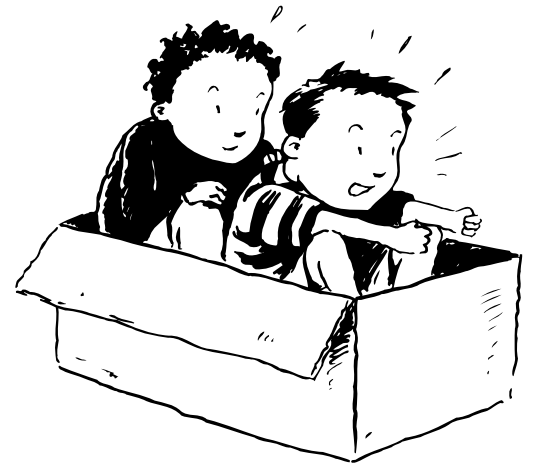
At this juncture in the lives of Michael and his grandmother, a community care team of helping people were brought together. They decided with the grandparent that the most important people in Michael's life should get together intermittently to listen to each other's diverse ideas in dealing with Michael and his grandmother's dilemma. This offered the merging of different perspectives and contributed to successful brainstorming. The team also was to bare witness, based on team alternatives, to the ensuing

progress, and became a vital audience reflecting back to Michael's and his grandmother's evolving changes. Perceiving a sense of empowerment in being able to make changes, and with enthusiasm of a new and caring audience, the family began building on their unique individualism, achievements, and an evolving new sense of their of their shared identity.

Looking for Turning Points and Teachable Story Moments:

A visible turning point occurred when Michael was 13 years of age and encompassed several simultaneous and converging opportunities. These included enrollment with a mentor from the *Youth and Families of Promise Program*, as well as a summer bus pass that provided for Michael a sense of distance and freedom to explore the potentials of the summer program. Michael made the public bus trip of many miles to his program on his own. The team felt this helped Michael rediscover himself. His newly found freedom gave him new connections with new meanings and an enhanced sense of agency to act on his own ideas and desires.

His world was now becoming mobilized by latent knowledge he had long possessed for his new explorations.



A major component of his identity was achieved relationally, facilitating memory of preferred history and redeeming past events. Identity development was further supported by the group with the provision of special activities, recreational opportunities, and wrap-around services for his personal needs. The Community Care team had a fund available offering low-cost instrumental resources. The team listened to the family's desires and supported Michael's involvement in such enriched activities as community soccer, after school camps, cliff climbing, the giving of small Christmas gifts, the privilege "wish card" which he used to raise a gerbil, and some pocket money from time to time.

We asked the mentor what personal qualities he observed in his young friend, Michael? Through their unique relationship and experiences, the mentor was observing uncovered stories of resourcefulness in Michael and that the boy showed knowledge of the heart. Michael had rediscovered his own attributes of self-acceptance, openness, genuineness, having a sense of humor, and curiosity. He began a positive journey into self-discovery as he recognized his part Mexican, part American heritage. He wrote in his memory book "to see something we must believe it."

The mentor was also changed by seeing parts of himself reflected through Michael's character which he himself did not know he had. He observed Michael beginning to endure hardships, sticking it out with someone, and not giving up. The mentor's personal sense of sustained advocacy was born in his and Michael's relationship. He stated, "Michael is an important person in my life."

Changes in Michael's life were also energizing to team members by their co-sharing of similar values and universal life themes. Michael's school achievement was a marked change, and associated with awards and higher grades. He was beginning to have a sense of his future, not just being stuck in the present moment. He started dreaming of a purpose in life with college, and a career. Gradual healing was afforded by implementation of more routines, offering predictability in his life. He was able to count on his mentor and other significant people giving him support. He attended school regularly, and on weekends he stayed with a distant Uncle. His prognosis had shifted and his newly adopted views of

life and himself offered a way to keep the promise for good graces for years to come.

Promoting change by measurement and accountability:

Over the course of Michael's change process the team was able to measure the progress he was making on a number of subjective and objective scaled variables. *The Youth Outcome Questionnaire*, a research-based instrument, shows changes in social and emotional behaviors over time and eventually showed quieting symptoms. By obtaining ratings on a scale of 1 – 10, with 1 the poorest, the team members observed the goodness of fit between Michael and his environment rise in basic foundation areas from 4 to 7-10. This shift was affected by greater relational security, enhanced attachments to other figures in his life, and hope for a different future all which were coming out of a sense of greater health, normalcy, and predictability. Michael's optimized daily strength ratings were raised from 3 in his early adolescence to 6-10 in middle adolescence in the midst of heart wrenching transitions with increasing periods of separation from his grandmother.



What was it about these occurrences and events early in adolescence in Michael's life that may have contributed to and influenced the turnaround? How long might it last? Might there be indications for early on preventive intervention impacts? Is the increase of resiliency a description of what may have happened? Is personal resilience influenced by individual experiences? And how might one wish to construct it? Our clinical team felt it was not just some idiosyncratic "pull yourself up by your bootstraps occurrence", but constructed by the new emerging story supported by rich new experiences and a loud and sincere cheering section acknowledging his real voiced changes. We are careful about just cheerleading as it may be perceived as patronizing and evaluative.

Our position has long been, by virtue of the empowering program name of ABLE vs "disabled" that within adaptive learning environments, resilient lived experiences can be shaped and modeled. Our program's experience suggests that older methods using only drill and practice and remediation of constitutionally-based information- processing deficits such as in the traditional resource pull-out model, is not sufficient by itself to determine quality of life and everyday adaptive functions.



More Storied Experiences:

We are moved to create more enriched storied experiences for other children also. Incorporating relationship-mediated experiences of significance, with associated opportunities to elaborate on what has happened, and its inherent meanings that become performed and acted upon can be a transforming experience. It can further modify and/or compensate for the learning blockages of attention, visual and auditory impairments as well as other developmental functions.

Our program belief substantiates Michael's reorganization of his past understanding of his very chaotic world that was interfered with by "seizure spells", panic and terror attacks, mood swings, and distorted thinking. We also found that his life could be buffered by enhanced supportive relationships under the consent of his grandmother. These included but were not limited to medical people, his mentor, the Community Care Team, his Uncle and new friendships he developed. All of these new connections provided a way for Michael to reorganize a new sense of security,

trust, additional satisfying interests, social approval, and esteem recognition. He was able to further communicate his desires in finding who he was, what he liked, and what he wanted through these new narratives.

Michael's preferred events included special and unique activities evoking a growing self-awareness and knowledge of his internal adaptability and personal qualities and formed attributes. He was able to integrate his evolving identity, and coupled it with his own professed values of honesty and authenticity, a knowledge of problem solving and making responsible choices, solving problems, staying with commitments, and sticking with challenges and finding ways of delaying gratification. These distilled and expanding stories of discovered competencies thicken experience and support new learning when they are retold, and are further reflected back to him by chosen people who helped in the process of constructing new story meanings from unique lived experiences. These stories further suggested an expectation of Michael's hopes and dreams with new purposeful outcomes, i.e. performing academically, being healthier without his panic spells or headaches, while physically growing and resisting problematic youthful impulses. His daily strengths continued to be magnified and augmented with new foundational assets in self-determined ways.

Long before Michael completed high school when he was just 14, he met a long- lost uncle who identified with him and took him on offering sanctuary and respite until a decision was made by his own grandmother to relinquish custody to this new individual. Michael flourished in school but has had temporary setbacks of depression through his young adult years and needed booster counseling and occasionally medication to deal with his unresolved past grief as well as encumbered and ambiguous losses. Most likely, he even became stronger as he learned to respond to his emotional confusion over the contradictions, complexities and multiple contingencies in his life and the many unacknowledged past good-byes.

As Michael further continued to build upon his successes, he continued to make positive progress in coping with his past. His later high school scaled confidence scores of 7-10 were made with self-predicted anticipation of future ratings of 8-10.

Michael, his grandmother, the Uncle, the Care Team, and all the people who worked with this situation and surrounding events were changed for their involvement with these experiences. The ABLE team has been privileged to learn from many of our families' sense of their own knowledge, skills and abilities. The truth is clear, complexity, deficits, and chaos within a messy world is never very far away from other positive life forces and their obscured and untold stories. These expressed strengths, competencies, and untapped resources can harness existing life capacities and inherent wellness of the body and mind in seeking for a sense of coherence and completeness for wellbeing.



Building Resilience through autobiographic memory:

Can we evoke and elaborate memory from our lived experience to build resiliency? This case presents the possibility for implementing alternative life scripted stories associated with ever-present unique outcomes. It helps if we truly believe this. By believing in this idea, we are always interested in participating with and listening to families in the search for those dismissed and covered up “sparkling moments”.

We feel that such moments offer valuable information for increasing the likelihood of seeing the world in a new way. This approach is very different from having a focus on problem solving in problem-laden environments, or in just pointing out strengths.

Some questions that we continue to ask with confidence are: Can health and developmentally-related challenges have improved outcomes from also looking for the positive in both the past and present lived experiences within the child, family, culture and community followed by building upon those with a new language? Can unique and novel experiences be promoted that are in synchrony with the family/child desires to make a difference in the present and future lives? Can this positive change from this kind of intervention be cost effective? Can what is learned in such cases be applied to other patients with such chronic illness? How can these practices be best taught?

Could these newly-brought-forth values through joint story-telling greatly enhance a new construction of character and ways of being? How might the self-styled stories bring forth new possibilities and ways of knowing? How is resiliency newly perceived or strengthened by reflecting back to these stories the ways the individual perceives experiences, listens, feels, views the world while exploring the voices they want to have. We have found that the revolving and recursive spiral of narrative connections generate great momentum and purposeful life directions in self-regulating ways for clients and workers alike. Michael is like the poster child for overcoming the dysfunctional maladies of life. Way to go Michael!!! Continue to tell your tales while performing them. We in the Village are your audience. Your life story is a part of ours.